# **Medication and its Side Effects**

How many of you have ever stopped taking your psychiatric medications with or without your doctor's help? Many people do. We stop taking them with our doctor's help and sometimes we stop taking them without our doctor's help.



# Why would we do that?

• We do not care about taking our medication? NO

• We do not care what the doctor wanted?
NO

• We like being "non-compliant"?
NO

• We do not care if our symptoms come back? NO

# So, why do you think people stop or alter their prescribed way of taking their medications?

- They do not have money to pay for them
- The side effects are so overwhelming that they give up
  - Weight gain
  - Blurred vision
  - Slurred speech
  - Stomach upset
  - Headache
  - Sexual side effects
  - Sleepy all the time
  - Unable to sleep
  - Always groggy
  - Muscle cramping

- Feeling agitated and anxious
- Dizziness
- Dry mouth
- Shaking
- Heart racing
- Feeling strange

(American Psychiatric Association, 1999-2003 <a href="www.healthyPlace.com">www.healthyPlace.com</a>)

- They want to see if they can be better without the medications
- The medications are not helping them
- No one listens when they complain about side effects



Why is this important? Many people stop taking their medications for many different reasons. Rarely do they stop taking them because they want to cause themselves or anyone else a problem. When someone comes to you and says they have stopped taking their medication...the first thing to do is ask them **WHY**? Then be ready to listen.



As Peer Support Providers, we **never** advocate for anyone to stop taking medication, to change medications, to begin to take our kind of medication, or tell them their doctor does not know what he/she is doing. However, we listen to why people have stopped taking medications. We try to understand their perspective. Peer Support Providers do not become angry or frustrated with anyone because they have stopped taking their medication. We understand how difficult it is to take psychotropic medication.

Making the choice to take medication happens to most people who take psychotropic medications almost every day. Each day the decision must be made to face side effects, or not have symptoms return. It is not always a clear or easy decision. As you become the listener, the person who truly understands, you can help the person discover solutions, advocate for changes, support them as they talk with their doctor or nurse practitioner. You can help them make a list of things that need to change. You can help them list and describe all of the side effects and come to a decision about which ones they can live with and which ones have to go.

Everyone wants to feel better. They want to be free from symptoms. People do not like to end up in an urgent care center, emergency room, or hospital. However, sometimes significant things happen that create symptoms that necessitate a visit to one of these treatment centers. It is important that you tactfully guide your work team to a place of understanding about medications and how it feels to take them. This part of your job may involve you sharing your story in very detailed ways to help people have a better understanding of what it feels like to take medication. It is one thing to know that a side effect of a medication is "gastric distress." It is another thing to let people know that you experience cramping and diarrhea **every single day** you choose to take your medication.



Part of your work will be to educate your coworkers with tact and skill about what it is like to take medication. Sometimes, people come in for help who cannot afford to take medication they know they need. You must become familiar with every community resource available that could help pay for the medications people need. There will be different community services in every area. Services available in your area should be discussed during this training. You should also begin building a reference list for yourself. Sometimes a community has already put together a comprehensive list of community services and agencies, ask about this.

There are lists of medications for various types of psychiatric diagnostic labels. You will become familiar with the names of many of them while you work. Here is a brief list of symptoms and the names of some of the medications given to relieve them.

# Prescribed for Psychotic Disorders and Schizophrenia

#### Atypicals:

- Risperidone
- Clozapine (Clozaril)
- Olanzapine (Zyprexa)
- You will notice that new medications appear on the market regularly. The more choices we have the more chance we have to find what will work for us with the least amount of side effects.

#### 

- Haloperidol (Haldol)
- Thiothizene (Navane)
- Trifluoperazine (Stelazine)
- These are the most commonly used medications of this group.

#### 

- Thorazine
- Trilafon
- Loxitane

# **Medications Commonly Prescribed for Depressive Symptoms**

- Selective Serotonin Reuptake Inhibitors (SSRIs)
  - Wellbutrin
  - Paxil
  - Prozac
  - Celexa
  - Luvox
  - Effexor
  - Zoloft
- ☆ Tricyclics
  - Nortriptyline (Pamelor)
  - Desipramine
  - Imipramine
- Mono Amine Oxidase Inhibitors (MAOIs)
  - Parnate
  - Nardil
  - Marplan

# **Medications Commonly Prescribed for Manic Features of Bipolar Disorder**

- À Lithium
- Anti-Convulsants
  - Tegretol
  - Depakote

# **Medications Commonly Prescribed for Anxiety**

- - Xanax
  - Ativan
  - Halcion

- Lorazepam
- Valium
- Klonopin
- Alzapam
- - Atenolol
  - Betaxolol
  - Carazolol
  - Talinolol
  - Propranolol (Inderal)
- - Paxil has an anti-anxiety component

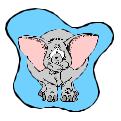
(NAMI, 2001)

### **Side effects of Psychotropic Medications**

We have discussed the fact that taking medications for psychiatric symptoms is one way to help us feel better. We have also mentioned that side effects are common when taking these medications. It is important to be aware of the side effects of these medications because people may mention what they are experiencing while meeting with you. It is important to listen to each person's experience. Do not assume they will have the same experience you may have had with the same medication. **Never** give advice on what medications to take or not to take. This is **not** part of your job. You may discuss your experiences and especially what you found helpful, but not in a way that gives advice or tells the person you are working with that they should do the same.

The most important and helpful part of your work with people around the medications they use to feel better, is that you understand that medications work well sometimes and sometimes they work with significant side effects. You will be the person who can encourage someone by understanding from your unique perspective. For instance, during the first few days or weeks that a new medication is begun, it may make you feel drowsy, dizzy, as if you are in a dream-like state. You may have nausea, cramping, crave food, or not want to eat at all. You, as a Peer Support Provider, understand that most of these feelings will pass as the body adjusts to the new

medication. You can support the person to continue through this uncomfortable and difficult time.



Here is a list of possible side effects that should be reported immediately (Saltz, B., Woerner, M., Robinson, D., Kane, J., 2000):

- Drooling or difficulty in swallowing
- Body spasms
- Body tremors
- Rigid muscles
- Inability to lie or sit still and/or feelings of inner turmoil or extreme nervousness
- Rash and/or itching
- Extreme difficulty urinating
- Sleepiness during the entire day
- Sexual difficulties
- Blurred vision
- Severe constipation

You may have experienced many of these side effects while taking your medication. You may wonder why they are included on a list that instructs the treatment team or provider be notified



right away. Some of these side effects may be present for as long as a person takes a specific medication, but some of them may indicate serious problems. It is only for the provider team to decide if the person should stop taking the medication or if they should continue. However, your job might include helping the person let their team or their medical

provider know that they are experiencing side effects.

#### Other Side effects

Here is a list of specific types of side effects (Saltz, B., Woerner, M., Robinson, D., Dane, J., 2000):

Extra Pyramidal Syndrome (EPS) - Many side effects are included under this type of symptom. These are side effects that affect movement. They are caused by the effect of antipsychotic medications on a specific area of the brain—the *extra pyramidal tract*. The older anti-psychotic medications are more likely to cause side effects resulting in difficulty controlling and coordinating body movements.

#### **₽** Extra Pyramidal Side effects:

- ♣ Akathisia This is an inability to sit still.
- <u>Dystonia</u> This is an impairment of muscle tone, usually seen in the head, neck and tongue.
- **Tardive Dystonia** These symptoms consist of slow, sustained and involuntary twisting movements of the arms and legs, body, face or neck.
- **▶ <u>Dyskinesia</u>** This is impairment in the ability to execute voluntary movement.
- ► <u>Tardive Dyskinesia</u> This is the involuntary repetitious movements of the muscles of the face, limbs, and trunk. It may include lip-smacking, grimacing, blinking, frowning, protruding lips and puffing cheeks. The person may or may not be aware that this occurs.
- **Pseudo Parkinsonism** This side-effect causes tremor, muscle rigidity, slow shuffling gate, and difficulty chewing, swallowing, and speaking.
- Oculogyric Crisis This is when the eyes are held in a fixed position usually up and sideways, for several minutes or hours.
- Opisthotonus These are severe muscle spasms that are prolonged and cause the back to arch acutely, the head to bend back on the neck and the heels to bend back at the legs. The arms and hands flex rigidly at the joints.
- Rigidity of Muscles This is stiffness in muscles that is often painful.

# Central Nervous System (CNS) Side effects

凸	Sedation
₽.	Psychomotor Retardation
Ð١	Lowered Seizure Threshold
<b>라</b> I	atrogenic Depression (This is depression caused by the treatment itself)

### **Anti-Cholinergic Side effects**

The body produces two chemicals: one is adrenalin. Most of us know something about adrenalin. Adrenalin is what the body produces when we are frightened or in a state of heightened alertness, like when we are on an exciting ride at an amusement park. Acetylcholine (a-settle-ko-leen) is the chemical in the body that keeps things running smoothly. It helps us think clearly, keeps a normal heart rhythm, keeps our mucus membranes and saliva glands working properly, and even keeps our stomach and bowels working normally. Many psychotropic medications affect these two body chemicals. Lots of medications we take affect these two body chemicals. For instance, if you take allergy medications, you may get a dry mouth or dry eyes and your nose may stop running. This is what the medication is supposed to do. It is affecting the acetylcholine levels to relieve allergy symptoms (Klung-Bern, M., 1993).

When one or the other of these chemicals is blocked...we are left feeling the effects of the other. The following list names some of the anti-cholinergic side effects that may occur when taking psychotropic medications:

- Dizziness (Take a moment to rest before standing up from sleeping, rise from a sitting position slowly.)
- ☐ Urinary retention (This may show up as decreased force of flow or a longer time for flow to occur, it may also allow some urine to remain in the bladder when urination is completed.)
- Cognitive changes (This might include confusion, a lack of concentration, forgetfulness, feeling disoriented.)
- Sleepiness (This may occur only the first few days or may be an effect that is lasting, which necessitates carefully timing when a particular medication is taken.)

- Rapid heart beat (A rapid heart beat can be a feeling or an actual heart rate that exceeds 110 beats per minute.)
- Constipation (Drinking more fluids will be very helpful when this side-effect occurs.)
- **Dry eyes** (Check with your doctor to find out the best solution for dry eyes.)
- Dry mouth (This common side effect can be difficult to cope with. Carry water with you. Chewing sugarless gum can help keep mouth moist. Low levels of saliva can lead to cavities and gum disease. It is important to brush and floss carefully if this is a side effect of your medication. If the person you are helping can not afford dental care, try to guide them to a community clinic that uses a sliding scale fee for service to help them receive good dental care about every six months.) (Klug-Bern, 1993, Driesen, J., 2003).

### **Controlling Side Effects**

When side effects occur, the doctor or nurse practitioner may prescribe some other medication to help relieve the symptoms. Some common medications used to help ease side effects are (Mueser, K. & Glynn, S., 1999):

- **◆ Cogentin** (reduces muscle spasms)
- **▼ Benadryl** (can help with insomnia, and itching that may result for certain medications while the body adjusts, or during an allergic reaction)
- **◆ Artane** (can relieve some muscle cramping and pseudo parkinsonism)
- **▼ Inderal** (helps relieve headache, lowers blood pressure, relieves some anxiousness)

Once again, the person should be referred to their doctor for help with side effects.

# Can a person help manage their symptoms and side effects? <u>Absolutely!</u>

### **Managing Symptoms and Side Effects**

While the symptoms of mental illness can be difficult to cope with, most of you have found that you have created certain methods of helping yourself through difficult times. Building a WRAP (Copeland, 1998) a Wellness Recovery Action Plan is a way to organize the skills that you have developed to work with your particular symptoms. It is important to remember that you are going to be the model of hope for people. You will be the example of a person who manages their symptoms to the fullest extent possible. This does not mean you will never have symptoms again, it does not mean that you will never become so ill that you must enter the hospital. It means that to the fullest extent possible for you and everyone who has a mental illness, we learn to manage our symptoms so that we can lead as full a life as possible. While you will make a more complete list of Wellness Tools in your WRAP, here is a short list of some ways to manage symptoms that are not medications:

- w Participate in therapy
- w Exercise
- w Participate in a support group
- w Do peer counseling with a friend (a very specific technique that allows each person to be heard and supported) Copeland, 1998
- w Go for a walk
- w Read a book
- w Play with your children
- w Play with your pet
- w Go for a drive in the country
- w Visit friends
- w Cook a really nice meal
- w Go to some garage sales or a thrift store

What works for you may not work for someone else. Everyone has their own methods or tools for managing their symptoms. Mary Ellen Copeland calls these methods of symptom management a Wellness Toolbox. As you begin to develop your skills as a Peer Support Provider, try to think of as many possible tools as you can. Be ready to share these as examples with the people you serve. You will find that the longer you work and share, the

more you will learn. Just when you think you have learned every possible Wellness Tool, someone will tell you something that has worked for them. Perhaps it will be something you never thought of, but you know it would work for you.

# Medication is one of many tools that can control symptoms!



#### **Techniques for Minimizing Side Effects**

Some tools for managing side effects have already been mentioned. When you have a dry mouth, carry water. It is easy to carry water today because of all the various containers in which soda and bottled water are available. Water will also help with constipation. Water is a better choice than soda or juice. Soda can have sugar or artificial sweeteners. Juice might need to be refrigerated. Talk to your doctor or nurse practitioner to see what they would recommend to help you with dry mouth.

Chewing gum or sucking on sugarless candy can also help with dry mouth. It is very important to keep saliva circulating in the mouth. Along with water, sugarless gum and candy can help.

Remember, a dry mouth can affect the health of your teeth and gums. So, these simple tools can help save your teeth (Driesen, J. 2003).

If your stomach is upset by the medications you take, perhaps taking them on a full stomach will help. With some medications, it is very important to watch what you eat while taking them. Your doctor or nurse practitioner will probably let you know about any food restrictions, but you should become comfortable with asking these questions and help the people you work with become more comfortable getting answers to their questions. Education and information are helpful tools to manage side effects.

Weight gain is common with certain psychotropic medications. Staying active and being careful about food intake are important tools to lessen weight gain. However, you should not stop eating and never advocate for someone to go on any particular diet. Again, if weight gain is causing someone you are working with to experience stress, upset, concern, worry, or sadness, help them talk with their doctor. Remember, each person has to balance the problem of side effects with the problem of symptoms. For each person, what is important will vary (Cline, T. 2002).

Sexual side effects occur frequently with some psychotropic medications. Sometimes these side effects pertain to arousal and ability to maintain erection. Sometimes, these side effects have more to do with an inability to achieve orgasm (Rosen, R., Lane,R., & Menza, M., 1999). Relief may be obtained through a change in medication, a change in the hour of day that the medication is taken or by prescribing something to relieve the symptom. Sexual side effects are not easy for most people to discuss. If someone discusses these issues with you, you must be sensitive and listen. Help the person you are serving find a way to communicate their difficulty to their medical provider. Perhaps they will want to write something down before their next appointment. Remember, having a mental illness does not diminish the human need for closeness and intimacy. Sometimes people may believe that coping with any side effect is necessary as long as a person is stable and their symptoms are controlled. While this may be important, living a full and complete life is also important. We are sexual beings and as such, this part of our life should not be overlooked simply because we have a mental illness.

If you experience dizziness or weakness because of your medication, the most important thing to remember is not to move around too quickly. It may feel like your equilibrium takes a moment to catch up with your movement. So, move a bit more carefully. Take a moment to rise from your chair or bed. This may prevent you from falling. You may want to carry a smart looking walking stick to give you extra support. Wear shoes that help you feel steady on your feet. Hold railings as you walk up and down stairs. These simple tools can help you with balance difficulties.





Managing medication and its side effects should be done with your medical provider. However, each of us must be an active participant in these endeavors. Working with a medical provider and communicating experiences and needs is an important part of symptom and side effect management. You must learn to be an excellent self advocate so that you can help the people you serve become their own self advocate.

References

Byrnes, G. (2001). Northern County Psychiatric Associates. Retrieved February 12, 2003 from www.ncpamd.com/side effects.htm

Cline, T. (2002). Newer generation medications benefit mental health clients. Retrieved February 12,2003 from www.odmhsas.org

Copeland, Mary Ellen (1998). Wellness Recovery Action Plan. Peach Tree Press.

Cronan, T., Hillix, W. & Bigatti, S. (2003) Retrieved February 12, 2003 www.healthinmind.com Driesen, J., (2003). Retrieved February 22, 2003 from www.driesen.com/dental\_side\_effects.htm

Klug-Bern, M. (1993). Confusion, Dizziness, Constipation: Not Necessarily Aging! Center on Aging, University of Kansas Medical Center.Retrieved February 12, 2003 from http://www2.kumb.edu/coa/Senior\_Press\_Article/Sr\_confusion.htm

Mueser, K. & Glynn, S. (1999). Behavioral family therapy for psychiatric disorders. New Harbinger, Oakland, CA.

Cowdry, R. (2001) National Alliance for the Mentally III. Retrieved February 2, 2003 from www.nami.org/helpline/medlist.htm

- Rosen, R., Lane, R., & Menza, M. (1999). Effects of SSRIs on sexual function: A critical review. *Journal of Psychopharmacology*, 19(1): 67-85.
- Saltz, B., Werner, M., Robinson, D., Kane, J. (2000). Side effects of antipsychotic drugs: Avoiding and minimizing their impact in elderly patients. *Postgraduate Medicine On-line*. Retrieved February 13, 2003 from <a href="www.postgradmed.com/issues/2000/02\_00/saltz.htm">www.postgradmed.com/issues/2000/02\_00/saltz.htm</a>

# **CLIENT RIGHTS**

### What are client rights?

Most mental health providers, and for that matter, providers of any type of services, have guidelines for customer service. Think of your local shopping center. Have you ever bought an item, returned home and found it broken, torn or inferior in some way? If so, you have probably gone to the customer service department to ask to return the item or exchange it. For people who receive medical care of any kind, it is considered your right to have competent, caring help for your illness or difficulty. Sometimes in the arena of mental health care, this idea is not as prominent. However, client rights are a fancy way of saying good customer service. In mental health care, the care is given to a person's mind, thought processes, and emotions. None of these things can be seen through an X-ray, measured with a thermometer, or blood pressure gauge, or looked at during an examination. Therefore, our own interpretations of our symptoms and experiences are the tool used to decide in what way we are ill and to what extent we are incapacitated by our illness. In other words, our descriptions guide our caregivers.

This method also is used when we have a pain of some sort and a doctor asks us how it hurts, when it started hurting, and a lot of other questions that help him/her form an opinion about why we might feel that pain. Whenever we are not feeling well in some way that cannot be measured or observed, our caregivers have to rely on our explanations and descriptions. Problems can occur in the mental health field because part of what is being treated...is our mind and thought processes. Therefore, unless the practitioner and others who are providing you with care and services are knowledgeable about how to listen to your explanations and experiences, and are able to see you as a whole person and not just your symptoms, you may not receive the best of care from the start. A person with mental illness may not be viewed as someone who is able to give clear descriptions or believable accounts of illness, because the very illness they are describing affects their mind. Some of the people we are serving will be especially vulnerable to poor treatment and negative attitudes of caregivers because they have developed ways of being that are difficult to understand.

Perhaps you are working with a person who lived all their childhood years with parents who were alcoholics. Perhaps these people became violent when intoxicated. That person grew up used to violence and upset. They probably had to develop ways of getting their needs met that were very intense. Perhaps they did not eat unless they cried, became violent the mselves and threw things around so they would be noticed, or they stopped asking altogether because it never helped anyway. These are behaviors they used to get their needs met. When they grew up, perhaps they never learned that they could meet their needs themselves, or that they did not have to yell and throw things to be noticed. Maybe they located a spouse or partner who came from a similar home life. So, they continue to live their life in the crisis mode, they are used to living this way.

Now, put this person in a mental health clinic for treatment and care. How might this person be
experienced by their treatment team? Think about it and write a few lines:

# Anyone care to share their thoughts?



#### **Role Play:**

**Person #1:** Imagine you are a case management provider or doctor. A person who is new to you comes in and has been having a lot of symptoms. They had to wait for you to finish with the last person you saw.

this scenario.

If you are not doing this role play, watch and think about both people and their experience. As a Peer Support Provider, how could you help? Here is some space for notes:

**Person #2:** Imagine you come from the family described above. You are used to having

to become very upset in order to be heard. Act out what you think might occur for you in

# Let's discuss your feelings and observations.

You might be thinking, what does this have to do with client rights? Just as the customer who bought a product that was broken or torn might be angry (because they possess the same coping skills as the person described above), a customer service representative would be instructed to listen and value the customer's opinion. In fact, what is usually taught to sales people is the idea that... **The customer is always right.** However, if you have an angry response to some problem in your mental health clinic, your response may be seen as symptoms, and not valid anger. When you are not listened to, respected, or heard, you are at risk for having your rights violated.

At the same time, we have a duty as Peer Support Providers to help people learn to advocate for themselves in ways that are helpful for them and that those who are providing care for them will "hear" and understand. When we talk about advocacy around people's rights, it is important to have a discussion about two important words:

# ASSERTIVENESS vs. AGGRESSIVENESS

ASSERTIVE	AGGRESSIVE
Explain the problem.	Assume people know what is wrong,
	or should know.
Speak with confidence.	Yell, so you will be sure to be heard.
If you do not achieve the response or	If you do not achieve the response or
help you need, start over.	help you need, yell louder and take
	on a menacing posture perhaps
	threaten them with filing a grievance.
If clearly explaining your needs	If yelling and being menacing do not
again does not work, ask to speak to	get what you want, an aggressive
a manager or supervisor.	response might be to hit or break
	something.
Continue up the line of management	At this point, people will surely be
until you achieve your goal or obtain	responding to you. They will be
information that helps you clearly	afraid, or they may have already
understand why what you want	called for help from some type of
cannot happen. This answer will	authority. However, <i>your</i> actual need
include alternatives.	will not be met because they will be
	working on their need to be safe.
If your needs are still not met at this	By now, you are either in custody, or
point, you will probably need to file	your "symptoms" have been treated
a complaint or grievance.	with medication, but you probably
	have still not accomplished your
	intended goal.

# Which way of managing a problem is the way you manage problems?



# Assertive

# **Aggressive**

Remember that there are other ways that people might learn to cope. Some people learn to be quiet and accept whatever happens. They do what they are told and try not to create "problems."

Sometimes this person is given lots of help because they go along with whatever is decided for them. However, sometimes the things that are decided for them are not what will really help. This person is sometimes called...**compliant.** The next table compares:

# ASSERTIVE VS. COMPLIANT

ASSERTIVE	COMPLIANT
Explain the problem.	Assume that people know what is
	wrong. Be quiet and do not make
	"problems."
Speak with confidence.	Speak quietly and do not expect too
	much, you are not important.
If you do not achieve the response or	If you are not getting the help you
help you need, start over.	feel you want, be quiet and just take
	what you can get.
If clearly explaining your needs	Do as you are told and accept
again does not work, ask to speak to	whatever you are given because at
a manager or supervisor.	least it is something.
Continue up the line of management	Realize that you are unhappy about
until you achieve your goal or obtain	what has happened, but do nothing, it
information that helps you clearly	would not help anyway. Feelings of
understand why what you want can	helplessness and hopelessness
not happen. This answer will include	increase, but they are familiar
alternatives.	feelings anyway.
If your needs are still not met at this	Feel frustrated and unheard, but be
point, you will probably need to file	quiet and turn against yourself by
a complaint or grievance.	isolating, and perhaps harming
	yourself. Do nothing to change the
	status quo because at least you know
	what it is.

Is this a familiar way of being for you? Perhaps it is exaggerated, but maybe not. How could you as a Peer Support Provider help the person who does not believe they are important to understand that they are? How could you help them to develop skills to help them be heard? Remember, for both the aggressive and the compliant person, their way of being is what they are used to, it is their experience. To change, even for the better, is very difficult. How could you help?

#### **Role Play:**

**Person #1:** You are the Peer Support Provider; the person you are working with is having terrible side effects from their medication.

**Person #2:** You are a person who finds assertiveness risky. You do not want to cause any problems or make anyone angry. However, you are having very uncomfortable side effects from your medications.

# Everyone who is not participating in this role play should watch and imagine themselves as a Peer Support Provider.



# Hiding from the problem does not make it go away! Help people you work with to be strong and confident self-advocates.

Each setting in which you work will probably have guidelines regarding client rights (person rights). You should become well acquainted with the procedures for helping people get what they need by helping them negotiate the system. However, you must also find the assertive person in yourself and not the aggressive or complacent person. Some basic rights might include:

- The right to express your needs
- The right to be treated with respect
- The right to be treated with dignity
- The right to have your cultural, racial, ethnic and religious needs respected
- The right to be religious or not
- The right to expect kind and empathic care

- The right to be listened to and heard
- The right to ask for necessary changes
- The right to be treated in a safe, clean and non-stigmatizing setting
- The right to be treated as a whole person and not an illness label
- The right to treat others with the same respect you deserve
- The right to pursue your dreams and goals
- The right to treatment to help manage your symptoms
- The right to receive information that reminds you that you can get well and live a full life, have dreams, maintain hope and look towards the future
- The right to choose a lifestyle that suits your needs

Each state and the federal government has guidelines for human rights. Even the United Nations has guidelines regarding the care and treatment of people who have mental illness. United Nations resolutions 37/194 and 46/119 "stand out" regarding medical ethics and the protection of persons with mental illness. They state, "mentally ill patients have the right not to be abused and they have the right to the best available mental health care (Okasha, Arboleda-Florez, Sartorius, 2000).

# **Project:**

If you have access to the internet, search for your state statutes regarding grievances, human rights, client rights, mental health care. Then, search for a local office of human rights and call them. Ask them for information about the rights of people seeking public mental health care. Become acquainted with the information you gather. Use it to help people advocate for themselves. Use it to advocate for yourself. You can become active in your participation in state government and outspoken in your commitment to clients rights. Write down what you discover and begin to compile a notebook of information that you can use to help guide your work. Bring some of the information you found to share with us before the last class.

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# References

Okasha, A., Arboleda-Florez, J., Sartorius, N. (Eds.). (2000). Ethics, culture and psychiatry: International perspectives. American Psychiatric Press, Washington, DC.

# **Treatment Planning with a Twist**

Treatment Planning is the hallmark of case management. Everyone who is receiving care that must be coordinated, in any setting, has a treatment plan. Sometimes it is given a different name; however, it is still a treatment plan. Some examples of names of treatment plans are:

- ➡ Individual Service Plans (ValueOptions)
- ⋄ Individual Change Plans (ValueOptions)
- ♥ Care Plan
- ♥ Daily Physical Rehabilitation Plan

What are some names you have heard for plans of service, care, or treatment?

How might a treatment plan differ in a strengths-based system? List some ideas you have. In your work, you may be able to advocate for strengths-based changes. So, take a few minutes and make your list.

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A well known recovery focused treatment plan is WRAP, Wellness Recovery Action Plan (Copeland, 1998). Mary Ellen Copeland, MA, MS who is a consumer and educator, created the WRAP by using information gathered from hundreds of people who have a diagnosis of serious mental illness. What she found was that people could learn what their symptoms were, how they progressed, and what kinds of things lessened symptoms or took them away altogether (Copeland, 1998).

Did you ever imagine that the WRAP is a kind of treatment plan? The thing that makes it so special is that it is created by the person. Sometimes, when a medical model is used, the people

working with us forget that we are the experts on our symptoms. Therefore, in every setting you work, you should become a tactful advocate for each person's participation in their own treatment planning. Perhaps one of the names of a plan you thought of could be developed in the setting in which you work.

What might a strengths-based treatment plan include? First, it might have a name that empowers people and lets them lead their treatment whenever possible. Look at your names above, do any of them seem empowering to you?

Who wants to share a name or two that you thought about?



A treatment plan usually contains some goals and/or objectives and some plans about how to accomplish the goals. If we make the plans FOR people, they are **our** plans, not theirs. However, when we are in the helping role, it is easy to think that we know best. You will need to be a tactful and helpful advocate for people's participation in their care planning.

As with all documentation, it is important to use strengths-based language. Strengths-based language keeps the person in front. It uses words that are not stigmatizing or hurtful. It uses hopeful language that never gives up.

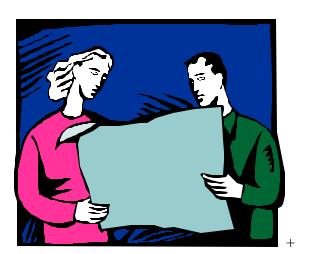
Using a partner, create plans for each other that have a strengths-based focus. You do not have to use your own experience, but you could. A sample grid is provided but you can use your imagination and make your own drawing of a plan you might use.

What do I want to do?	How can I do it?	Who can support me?
1.		
2.		
3.		
	Here's space for you	ır ideas!

Anyone care to share?

# Questions to ask yourself when working with someone on their plan:

- Am I working *with* the person?
- Mark Am I listening to their ideas?
- Am I telling them what to do instead of letting them take the lead?
- Do they know that we can recover?
- Do they know about WRAP?
- Have they created a WRAP?
- Are we using information from their WRAP?
- Mark Am I helping them use non-stigmatizing language?
- Is the team supportive of this process?
- How can I help the service team support this individual's process and ideas?
- Am I restricting their growth and well-being? How?



# References

Copeland, Mary Ellen (1998). Wellness Recovery Action Plan. Peachtree Press.

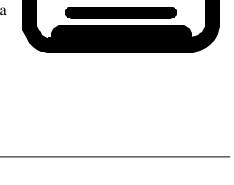
# **Understanding Court-Ordered Treatment**

A discussion on court-ordered treatment is likely to be difficult. However, understanding the process and the reasons behind this type of treatment decision may be helpful. The more knowledge that you as a Peer Support Provider have about this process, the better support you can give someone who may be experiencing the process.

While it may feel that forced treatment is inflicted as a punishment, it is usually done because your caregivers, or the caregivers of the people you are serving, fear for your or their safety. Even if a person is considered a danger to others, usually they are cared for against their will so that they will not cause harm to someone else, thereby causing themselves harm. The harm they cause themselves might be the pain of knowing they have harmed someone. It may be jail for causing harm. Treatment might be ordered to protect the person from harm that could result from their actions against others. All of these things would

Caregivers want to see the people they serve feeling well and living a full life. Preventing Court Ordered Treatment is part of preparing an advance directive. It is also part of creating and using a WRAP. The more planning that is made around a person's particular set of symptoms, the better chance they have of avoiding forced treatment.

ultimately cause harm to the person.



Do you have experience with court-ordered treatment?				

What would have helped you with that experience?
<del></del>
Twy to remember what led up to that action being taken to incure your cofety or the cofety of
Try to remember what led up to that action being taken to insure your safety or the safety of
others.

Even if it is difficult, does anyone feel he/she could share this experience with your learning community?

Remember, one of the most important gifts you bring to your peer relationship is the ability to share your lived experience. Forced treatment may not be a pleasant experience, but it could be the reason someone is able to begin his or her recovery process. Supporting people through the process can provide the people you serve with necessary help to make the most of this hard situation. If they are having difficulty with medication side effects, help them to learn advocate for lowered dosages or a change to a similar medication that will have the same therapeutic effect, with side effects that are more tolerable. Changing medications or lowering dosages may not always be possible, but presenting needs in a clear and meaningful way might increase the chances.

However, the most important tools by far are preparation and prevention. If people learn to identify and manage their symptoms, they may never end up in treatment that is ordered by the court. Since treatment by court order usually involves a hospital stay and about a year of forced clinic visits, it would be much better to become so aware of your symptoms that you are able to prevent a crisis altogether, or at least identify a crisis soon enough that you are still able to recognize your need for help. As a Peer Support Provider, an important part of your job will be to help people prepare for crisis in such a way that they may never have to experience treatment by court order.

Will you be successful every time? Probably you will not. However, even if someone you are serving ends up in court-ordered treatment, you can support them through the process and let them know that they can prevent it from occurring again. You do not need to feel as if you have failed. The most important thing is that the person is still alive to work on his or her problems and hopefully has not caused harm to himself or herself or to anyone else. In other words, try to understand that even if their care is forced, they are getting care that in the end can change their life for the better.

# What is the process for court ordered treatment?

When someone begins to have symptoms that others perceive as dangerous to themselves or to others, steps must be taken to help protect the person and those around them. If the person is having serious symptoms and they are able to recognize their need for care, then steps can be taken with them as a part of the process. Even if the person has to go to the hospital, they can go without being forced. If, however, symptoms increase to a level where the person no longer realizes that they are in need of care, steps can be taken to **petition** the person. Creating a petition develops a request for the court to examine evidence that you are dangerous to yourself or others. You could be dangerous to yourself because you are threatening to kill yourself. You could be dangerous because you refuse to eat and are losing weight to such an extent that you are at risk. You could be dangerous to yourself if you no longer recognize that walking in the middle of a main road at rush hour is dangerous.

You could be a danger to others if you are thinking that you must harm someone. If you have children and you no longer understand that they need your care, you may create risk to the children. If a person is unable to control rage, they might be dangerous to others. There are many reasons the court could find a person a risk to themselves or others.

The next step, aside from being kept safe, is that you will be given a hearing before a judge. That judge has been appointed to oversee petitions and decide if the petition is valid. If it is not, the judge will not order someone into forced treatment. If the judge believes it is valid, he will deliver a court order for treatment. This treatment could include hospitalization or outpatient commitment. Outpatient commitment means that you must take medications prescribed to you for as long as the order is in force. Sometimes injections are given. However, all appointments must be attended, or you can be retrieved and put into the hospital again without the order of a judge.

No one who is involved in court-ordered care likes to see it happen. This list of people includes the person being committed, their case management team, the doctors, therapists, or family member and supporters. It is the last choice for care. Every effort should be made to help prevent this process from occurring.

# **Psychiatric Advance Directives**

Psychiatric advance directives can be an important tool in maintaining control of your circumstances even when you are ill. Advance directives are used in the medical arena to help guide the care of terminally ill people. They give instructions to family members and loved ones so that even if the person becomes unable to give instructions, their loved ones will still know how the person would want them to proceed.

We think of advance directives when we think of life support. If someone becomes very ill, he may ask that no extraordinary measures be taken to prolong life if he is not expected to recover. The idea of using advance directives in mental health care is a new idea. It is so new that it might not be supported by law in the state in which you live. The WRAP Crisis Plan is a form of advance directive. The Crisis Plan is a tool to help you give information about yourself to those who are your loved ones and supporters so that they may act on your behalf if you are unable to make decisions about your care.

In your role as a Peer Support Provider, you may be helping people to create WRAP Plans and Crisis Plans that will support them and guide their care if they become too ill to make decisions. A Crisis Plan can even help you if people feel they are becoming ill and need help to avoid a crisis. The more personal responsibility a person takes for her care, the more empowered she feels. It is a common belief that most people who have a mental illness do not want to be responsible for their care, or they do not have the wherewithal to be able to decide what to do. The WRAP and Crisis Plan help people to identify what needs to occur when they are well enough to make these decisions.

# Crisis Plan

Have you ever wished you had a plan in place so you could have stayed out of the hospital?
<del></del>
Do you have a WRAP Crisis Plan? ☐ yes ☐ no
Do you believe that you can help someone create a plan that will help them identify people and
things that will help them prevent a crisis or help them to get the help they need if they are in a
crisis? It is important that you develop your own crisis plan so that you can help others make
theirs. One of the gifts that peer support providers have to share is their personal experience.
Even if you have never been hospitalized, you can help someone create a plan for themselves
that guides them in a crisis.
Why is it important, when you are in a crisis, for someone to know how you look when you are well?
How do you know when you are starting to move into a crisis? What things begin to happen internally or in the world around you?

What things help you when you are starting to have a crisis?
How do you know?
How do you know when you are feeling better?
Who can you count on to help you when you are feeling very ill?
How do you know they will help?

These questions can help you guide someone to create a plan in advance—an advance directive. As you wrote out your answers, did it strike you that you have lots of knowledge about yourself and your symptoms? You also know who you can count on and why. Knowing how you are when you are well may take some thought and work, but as you go through the process, it will help you to learn how to help someone else identify how they look when they are well.



Creating an advance directive is like getting a team prepared for a game. You make the plans, decide what to do if things do not go the way you planned, identify the players who will carry the ball, kick off, tackle and run, and you plan with the resolve that your team will win. It is the same with creating a plan for care. A plan is made about what to do and when. You plan for unforeseen problems. You identify each participant and supporter's role. You plan as if everyone will do their job and things will work as they should.

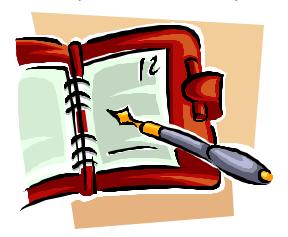
One important thing to remember about planning for a game or planning for your care...the important "players" must understand and agree to their jobs. If they do not understand what you need them to do, they cannot do the job. If the quarterback does not understand it is his job to throw passes, he may think he can only run with the ball. So give people the plan, talk it over with them. Help the people you serve identify who their key "players" are and support them in getting their whole team on board. People may have a lot of fear about telling their deepest secrets. They may believe that no one loves them enough to want to help.

A person may start with one supporter. They may start with none. If they have few or no supporters, then help them identify the ways that they can start developing a community of supporters. Help them find ways to share this part of themselves without shame. A psychiatric diagnosis is no different from a diagnosis of any other illness. Even if some supporters turn their backs on the people you are serving, stand by them and do not give up. People can usually find someone to help them.

Planning for the unexpected or planning ahead for what is expected can create a sense of control and relieve a lot of stress. Just knowing that someone will be feeding the cat or bringing in the

mail if you go in for care, can relieve a lot of stress and perhaps help someone obtain help before they reach the crisis point. Perhaps it will allow them to stay 23 hours in an urgent care center, rather than stay a week in the hospital because they were afraid to ask for help and waited too long to seek care.

One other important thing to do with an advance directive is to write it down and be sure that the people who need copies, have copies. Having the document typed up and notarized is important. When the document is notarized, it may be taken more seriously.



Taking some hard but purposeful steps to create a plan before a crisis occurs can help people stay in control of their lives even when they are unable to act for themselves. Their wishes and requests are more likely to be honored if they are written down and acted upon by chosen supporters. Helping people plan ahead can be an important part of your job as a Peer Support Provider.